

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Care Delivery and Research Sub-Group

October 22, 2012

Run time: 9:00 to 10:00

RI Hospital: Aldrich Building 5th floor.

Present: Peter Snyder, Kathy Heren, Steve Salloway, Ed Stopa, Elaina Goldstein, Ana Tuya Fulton, Nasser Zawia, Leslie Fontana, Lindsay McAllister

1. Dr. Snyder welcomed all participants and reviewed the background of why the state has begun this effort to create a state plan.
2. Dr. Salloway asked if there would be any dedicated funding and Lindsay explained that this effort was intended to serve as advocacy tool. We have to be specific and targeted in our requests and/or recommendations in order that the General Assembly may view this report as a resource and assembly of action items.
3. Dr. Snyder added that the charge to the sub-committee from the full group is very large and we therefore want to focus on the intersection between care delivery and research. One premise is that good clinical care includes access to research, and in fact, access to ongoing therapeutic trials should be the standard of care. To the extent that those in the community are not connected to the research community, it is a disservice. Solving that problem alone is likely enough for one sub-committee to tackle alone. We need an active way of encouraging participation – perhaps a statewide registry (online) that could folks could hook into – perhaps two points of entry. Providers and families of patients will need access.
 - a. Between Care New England and Lifespan there are 20 clinical trials. That is a lot for a state this size.
 - b. Clinicians aren't likely to know where to go or how to get information about who is qualified. We also need to be able to provide quality information to patients and in a timely way. A lot of information is coming out about the potential lifestyle, dietary and exercise, changes that can be preventive.
4. Dr. Tuya Fulton brought up the idea of a twice-yearly state sponsored symposium for clinical and research updates so that care providers and families can have access to ongoing research updates and clinical trial results.
5. Elaina Goldstein added that she is concerned about the developmentally disabled population with and those with Alzheimer's. There are very few doctors who treat these dually diagnosed patients. Her project at URI is really focused on coordinating services and finding physicians who will care for this population.
6. Dr. Snyder advised that the research she is doing will greatly inform new systems of care. This is critical and we will want to learn from that experience and follow up. I don't think this committee can manage all aspects of care to get at service delivery from different aspects.

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7. Dr. Ed Stopa suggested that a registry to plug people into the system is needed. There could be a number of trials or help with access to specific expertise that's tailored toward that particular part of the disease – **one stop shopping. Once you've plugged in, you can pivot into different areas of service and various needs. This would also enable long-term tracking of people with the disease and inform a quality control process.**
8. Lindsay McAllister shared some information on the DC Area Geriatric Education Center Consortium – a cross-institutional effort to improve education & training for health care professionals.
 - a. One of the Consortium's primary programs is their Master Faculty Program, which meets twice yearly with in-house teaching time, faculty mentors, a two-day retreat, group projects, and required participation in humanities and arts in gerontology.
9. Dr. Zawia asked about promoting and connecting basic pre-clinical drug discovery research into the larger system.
10. Dr. Snyder – The National Plan (NAPA) discusses connecting clinical efforts into the state efforts and making sure that clinical trials are identified. We should take NAPA and, under each section, editorialize and make it pertain to RI.
 - a. Services at URI, for example, or departments or centers of expertise that we wouldn't know about otherwise, should be categorized into sections. Please edit the document in each section and we can pull it all together into a single document.
11. Dr. Stopa pointed out that there are many plans and asked whether we have looked at other state plans?
12. Dr. Snyder answered that we've looked at many of the plans and VT is just one of them.
13. Lindsay McAllister pointed out that VT's is viewed as one of the exemplary state plans by the national association and it is also one of our regional neighbors with a similar university system. That is why we started with VT, but we've also looked at MA, TN, etc. We had to start somewhere as there are over two dozen state plans.
14. Dr. Zawia shared that there is a document that surveys these resources at URI and we can share it with this group.
15. Dr. Snyder – **There is a nascent effort between Butler and Lifespan to begin a registry. It's a small cottage industry project and isn't robust enough to meet long-term needs, particularly outside of those institutions. It is a start, but we can blow it out and make it something that could really be usable by others.**

There are logistical questions – why would the registry reside, how could each institute have access to it? What are the HIPAA concerns?

16. Elaina Goldstein asked about the Quality Institute's Health Information Exchange suggesting that it sounds like something that could work.
17. Dr. Snyder agreed that would be worth looking into and suggested that Lindsay could follow up.
18. Dr. Stopa added that a place where best practices can be shared is needed. There's no better way to go from A to Z than to ask how to get them the best care? A one-stop shop for primary care doctor in Southern RI and plug them into the state registry and everything can go from there.
19. Dr. Snyder recommended that research should be thought of broadly – anything evidence based.
20. It was suggested that large providers like Roger Williams need to be involved. Lindsay will follow up on this.
 - a. Need a list of people who have a large patient population – the key providers caring for these people – between Brown, Lifespan and Roger Williams
 - b. Dr. Tuya Fulton takes care of a lot of the advanced patients, but most who are in the moderate state – the two memory centers see most of the new cases. The continuing care is really out in the community – its very diffuse.
21. Dr. Stopa said that the brain donation system shows us a pattern – **early-on folks get referred to Memory Centers and they get evaluated. Eventually, they become institutionalized and they seem to slip through the cracks** so that there's a 5-10 year period where families feel no one has been doing an evaluation on them. **We need more data on those people.**
22. Kathy Heren – **start with money-making institutions, which all tend to have dementia units.**
23. Dr. Tuya Fulton added that there are so many of them and they cannot all be cared for in the memory centers. Vast numbers are cared for by primary care doctors in the community or medical directors at the nursing home. **The challenge is to identify the clinical and basic-level research. We know a lot about what works and we need to communicate it to all those who are providing the care within institutions.**
24. Elaina Goldstein suggested that its important to know the research for those who want to provide the best care, but just don't know where to find the information.

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The Health Information Exchange is really the place for this data. Living Rite Centers, assisted Livings, getting the best information and free flow, easy access.

25. **Dr. Snyder concluded that we have consensus that this is what the sub-committee should be focused on – the Free flow of information for providers across settings that is easy to access.**
26. **Dr. Salloway added that we need to try to catalogue what is going on in research across the state. There are a lot of resources and having that information collected and available would really help.**
27. Leslie Fontana, from RISD, said that she is starting to visualize a map of how that registry would work – like AARP's Wikipedia function that would have an easy interface for both doctors and families, and it could be in several areas. She can map what an interface would look like and bring it back to this group.
 - a. Dr. Stopa added that this is where the state should come in and run with this idea and provide the resources.
 - b. Dr. Snyder agreed; it is this kind of specific ask that we could price out that could potentially be taken up by the legislature.
 - c. Dr. Zawia said that we have so many resources in the state and it is amazing what you find once you start looking.
28. Dr. Salloway – **there are two different sides to this website idea with regards to research** (those who are interested in clinical trials and then be contacted – patients or families), **a go-to place for patients or families to find out information and options for care and services** (links, etc.). Are the two the same? Arizona has a state registry for research where anybody who wants to can sign up but it may not necessarily be for care and services.
 - a. Dr. Snyder suggested that there isn't any reason they cannot be approached in the same way.
 - b. **Elaina Goldstein said that the DEA was creating a resource center. We may want to see where the POINT has gotten to so far, and see if you could link the two resources eventually.**
 - c. **Dr. Salloway added that the Alzheimer's Association has something. Anyone who wants to find out about care or research – many links, link to a registry, etc. It could be hosted by ALZ. Association.**
 - d. Dr. Stopa suggested that maybe we shouldn't call it an Alzheimer's Registry because you excludes people with other dementias.
 - e. Elaina Goldstein thought it was properly "neurological disorders" like brain injuries? Are they similar? Can the affect be the same?
 - f. Dr. Salloway suggested that there is overlap, but the magnitude of this problem is so great that if you add on other illnesses that are very much in need...
 - g. Dr. Stopa said you want to be able to capture folks who don't know or who aren't ready to admit that its Alzheimer's.

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- h. Dr. Zawia added that the Alzheimer's name is very familiar in the community at this point, so there's merit in using the name.
 - i. Dr. Snyder also felt that if we want to partner with the association it would be necessary.
 - j. Dr. Stopa said this assumes everyone will simply assume its Alzheimer's. How do you plug them in early? Those are the people who will be searching the web.
 - k. Elaina Goldstein added that if we're focusing on how to prevent the progression, we need to capture the early folks.
29. Dr. Snyder shared that he'd given a talk last week at a library in Newport and they'd had about 50 seniors. Many are quite healthy and we had about 15 come up to them to talk about clinical trial participation. **If we had a card to hand out to drive them to a resource to know where the get involved with a trial it would have been great...**
- a. Dr. Zawia added that people in Boston know where to go. People who have memory disorders in RI don't necessarily know where to go.
 - b. Dr. Stopa suggested that there may still be a stigma associated with having the disease and we want to be able to connect with them.
 - c. Elaina Goldstein felt going with prevention and early detection is important.
30. Dr. Snyder summarized that there are a few "to do's for the sub-group."
- a. Edit the national plan. The VT plan can be an example. We will send out a word document with only the research parts of the plans.
 - b. Under any section, if you have anything to add: gaps, highlights, additions, successes, Centers of Excellence that you want to make sure are mentioned – do so, and send it back to us and we'll compile into one document and it will be editable moving forward.